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Title

Assessing Functioning in adolescents with Chronic Fatigue Syndrome: Psychometric properties and Factor Structure of the School and Social Adjustment Scale and the Physical Functioning Subscale of the SF36

Running Head

Psychometrics of SSAS & SF36PFS in paedS CFS

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Conflicts of Interest

TC is the author of several self-help books on chronic fatigue for which she has received royalties. TC /KCL has received ad hoc payments for workshops carried out in long term conditions. KCL have received payments for TC's editor role in the Journal of Mental Health. KR has co-authored a book with TC called "Overcoming Chronic Fatigue in Young People" for which she receives royalties. ML and SV have no conflicts of interest to declare.

Ethical Permissions

Approval was granted by NHS research ethics committee (LREC, ref 08/H0807/107), and by the Research and Development departments at the South London and Maudsley (SLaM) NHS Trust, and Great Ormond Street Hospital. Approval for the collection of routine outcome measures was also given by the clinical audit committee of Psychological Medicine Clinical academic group of SLaM.

Abstract

BACKGROUND: Chronic fatigue syndrome (CFS) has a major impact on functioning.

However, no validated measures of functioning for this population exist.

AIMS: We aimed to establish the psychometric properties of the 5-item School and Social Adjustment Scale (SSAS) and the 10-item Physical Functioning Subscale of the SF-36 in adolescents with CFS.

METHOD: Measures were completed by adolescents with CFS (N = 121).

RESULTS: For the Physical Functioning Subscale, a two-factor solution provided a close fit to the data. Internal consistency was satisfactory. For the SSAS, a one factor solution provided an adequate fit to the data. The internal consistency was satisfactory. Inter-item and item-total correlations did not indicate any problematic items and functioning scores were moderately correlated with other measures of disability, providing evidence of construct validity.

CONCLUSION: Both measures were found to be reliable and valid and provide brief measures for assessing these important outcomes. Henceforth, we recommend that the Physical Functioning Subscale be used as 2 subscales in adolescents with CFS.

Keywords: physical, academic, functioning, social, CFS, adolescents

BACKGROUND

Chronic fatigue syndrome (CFS) is diagnosed when an adolescent experiences unexplained chronic and severe fatigue, lasting for at least 3 months; the fatigue does not remit with rest and causes significant interference in their functioning (NICE, 2007; RCPCH, 2004; Sharpe et al., 1991). Additional symptoms may include nausea, dizziness, hypersensitivity to noise, light or touch, pain, post-exertional malaise and cognitive problems (NICE, 2007).

Approximately 0.1-2% of adolescents are affected by CFS (Brigden, Loades, Abbott, Bond-Kendall, & Crawley, 2017). Physically, adolescents with CFS can experience limitations in their ability to perform daily activities, such as walking short distances and climbing the stairs (Garraalda & Rangel, 2004). Beyond the physical impact, the impact of CFS on school functioning is also substantial; adolescents presenting to specialist services attend an average of 40% of school, miss an average of 1 year of school, and struggle to return to full time education (Bould, Collin, Lewis, Rimes, & Crawley, 2013; Crawley & Sterne, 2009; Sankey, Hill, Brown, Quinn, & Fletcher, 2006). Their symptoms also prevent them from fully engaging in social relationships with their peers. The resulting lack of social life and of academic achievement impact on identity and contribute to a sense of failure for the adolescent (Parslow et al., 2017).

Given the significant impact that CFS has on physical, academic and social functioning, one of the main aims of treatment is to improve functioning. Therefore, patient reported outcome measures frequently include assessments of functioning. It is important to ensure that the measures which are commonly used for these purposes are valid and reliable.

Physical functioning captures activities of daily living such as walking and getting dressed (Tomey & Sowers, 2009). In paediatric CFS samples, physical functioning is often

assessed using the 10 physical functioning items of the well-validated health survey, the Short-Form 36 (SF-36) questionnaire (Crawley & Sterne, 2009; May, Emond, & Crawley, 2010). Using this measure, 98% of young people with CFS presenting to specialist services reported being limited to some degree in activities of daily living and/or mobility (Crawley & Sterne, 2009). Worse physical functioning was also associated with other unfavourable outcomes, including increased fatigue, pain and mood (Crawley & Sterne, 2009). The Physical Functioning subscale has also been used as an outcome measure in treatment trials in paediatric CFS (Brigden et al., 2016; Chalder, Deary, Husain, & Walwyn, 2010; Crawley et al., 2017; Lloyd, Chalder, & Rimes, 2012). Despite its extensive use, detailed psychometric analysis has not previously been published.

School functioning can be thought of as multidimensional, encompassing not only academic achievement, but also social skills development, peer interactions and relationships, and extracurricular activities. A recent review highlighted the lack of validated questionnaires for assessing the school and social functioning of adolescents with CFS (Tollit, Politis, & Knight, 2018). The proxy for school functioning that is most commonly assessed as an outcome measure is school attendance (Chalder et al., 2010; Crawley & Sterne, 2009; Lloyd, Chalder, & Rimes, 2012). This is an important but unsubtle measure that does not fully capture the extent to which symptoms like cognitive difficulties impair functioning and engagement within the school environment. Neither does it capture the social impact of the illness (Tollit et al., 2018).

In adults of working age with CFS, the Work and Social Adjustment Scale, WSAS (Mundt, Marks, Shear, & Greist, 2002) has been used extensively in research, including as an outcome measure in randomised controlled trials (Burgess, Andiappan, & Chalder, 2012; Deale, Chalder, Marks, & Wessely, 1997; Quarmby, Rimes, Deale, Wessely, & Chalder, 2007;

White et al., 2011). The WSAS is a brief self-report measure assessing functioning in work, domestic, social and leisure activities and close relationships. It has been found to be reliable and valid in an adult group of patients with CFS (Cella, Sharpe, & Chalder, 2011) and is appealing for use with adolescents who are fatigued due to its brevity and relative simplicity. The adapted version, designed for adolescents, has been used as an outcome measure in a treatment trial (Lloyd, Chalder, Sallis, & Rimes, 2012), but detailed psychometric analysis has not previously been published.

CFS impacts significantly on adolescents' physical, school and social functioning. Therefore, these aspects of disability associated with the illness are important to measure during clinical assessments and as an outcome measure following treatment. This study aimed to establish the psychometric properties and factor structure of a) a commonly used physical functioning measure, the Physical Functioning subscale of the SF-36, and b) an adapted version of the WSAS, the School and Social Adjustment Scale (SSAS), a measure of school and social functioning, in adolescents with CFS.

METHOD

Participants

The data for this study were collected as part of a larger study. The inclusion criteria were adolescents between the ages of 11 and 18 with a confirmed diagnosis of CFS (NICE, 2007), attending an initial assessment at one of two specialist CFS units in London. All eligible consecutively referred patients who attended an initial clinical assessment appointment at the units were invited to participate. Data collection at the main study site, where 91% of the participants were recruited, commenced in August 2010 and continued

until October 2017. Eleven participants were recruited at a second site between August 2010 and January 2012. Across both sites combined, 207 adolescents attended for an assessment, 135 of whom met the eligibility criteria. One hundred and twenty-one (89.6%) participated in the study (see Table 1 for participant demographics).

Our sample size of 135 is not as large as one often uses in latent trait models, yet it yields a 13.5 to 1 and 27 to 1 participant/item ratios. These ratios are higher than the common rule of thumb on the field (8-10 to 1 ratio or less, see Cattell, 1978). In addition, the simplicity of the potential sample structure expected due to the small number of items (one or two factor models), allows for the method to work adequately (see de Winter et al, 2009, for a simulation study on sample size for factor analysis).

Measures

Participants were asked to provide information on important demographics.

Physical Functioning –the Short Form 36 physical functioning sub-scale (McHorney, Ware Jr, & Raczek, 1993; Ware & Sherbourne, 1992), referred to here as the Physical Functioning Subscale, is made up of 10 items, describing various activities of daily living (see Table 2). Items are rated on a 3-point scale and responses indicate the extent to which the respondent thinks that they are limited by their health in each activity. Items were coded as 0 (yes, limited a lot), 5 (yes, limited a little) and 10 (no, not limited at all). Thus, higher scores indicate better functioning, with a total possible score ranging from 0 to 100.

School and Social Functioning – The School and Social Adjustment Scale (SSAS) is an adapted version of the Work and Social Adjustment Scale (WSAS), which was designed for use in adults of working age (Cella et al., 2011; Mundt et al., 2002; Thandi, Fear, & Chalder, 2017). It is composed of 5 items corresponding to work, domestic, social and leisure

activities and close relationships in adults, each of which the respondent is asked to rate on a 0-8 scale. Higher scores are indicative of greater impairment in functioning, with a total possible score of 0-40. For use in adolescents, the word 'work' in the first item of the WSAS was replaced by the words 'school/college', and the scale was therefore called the 'School and Social Adjustment Scale' (see Table 2).

Fatigue – the Chalder Fatigue Questionnaire, CFQ (Chalder et al., 1993) is an 11-item scale which measures the severity of physical and cognitive fatigue. Items are rated on 4-point scales with reference to the past month. Higher scores indicate more severe fatigue. In the current study, Cronbach's alpha was .89 for the total score.

School attendance - Adolescents were asked to report how many full days and half days they attended school in an average week and this was converted into a percentage. This way of assessing school attendance has previously been used in paediatric CFS samples (Chalder et al., 2010; Crawley & Sterne, 2009; Lloyd, Chalder, & Rimes, 2012; Stulemeijer, de Jong, Fiselier, Hoogveld, & Bleijenbergh, 2005).

Sit-to-Stand test (SST) – The SST is an objective test of physical functioning which encompasses functional strength, endurance and exercise capacity. The participant is instructed to perform 5 consecutive sit-to-stand manoeuvres, starting from a seated position in a chair, as quickly as possible (Csuka & McCarty, 1985). The speed of completion is used as a measure of physical strength. This test has good reliability and validity (Bohannon, 2011). SSTs have previously been used as an outcome measure in adolescents with CFS (Gordon, Knapman, & Lubitz, 2010).

Procedure

During the patients' first assessment, the assessing healthcare professional discussed the study and shared a participant information sheet. Patients had the opportunity to discuss the study in more detail with a research assistant after the clinical assessment. Subsequently, both adolescent patients and their parents provided written consent to participate in the study. Participants completed a questionnaire pack which was returned to the study team. During the initial phase of the study (2010-2012), participants were also invited to complete a series of laboratory tasks, including the SST.

Data Analysis

Data analysis was conducted using SPSS 24 (SPSS, Inc, Chicago, IL) ,Stata 15.0 (StataCorp., 2017) and Mplus 8.4 (L. K. Muthén & Muthén, 1998). All available data were used in the analyses using a listwise approach, as the number of missing values was very low (less than 7%, that is 4 individuals with incomplete data on the Physical Functioning Subscale and 8 individuals with incomplete data on the SSAS). Imputation for missing data was considered unnecessary.

As no a-priori expectations or theoretical guidelines exist on the dimensionality of the scales, we used Exploratory Factor Analysis, rather than Confirmatory Factor Analysis. Exploratory factor analysis for categorical data (often referred to as item factor analysis) via the weighted least squares estimator (WLSMV; Muthén, du Toit, & Spisic, 1997); rotation (Promax) was employed to investigate the dimensionality of the ten items of the Physical Functioning Subscale, when used as a standalone scale. This approach was followed as the items were rated on a three-point ordinal scale. On the contrary, the common factor model was used for the five SSAS metrical items. The maximum likelihood method was employed,

to account for the missing values. All latent variable models' analysis was conducted in Mplus.

The model fit was evaluated using measures of absolute and relative fit. Specifically, we report on the relative chi-square ($\text{rel } \chi^2$: values close to 2 indicate close fit (Hoelter, 1983)), the Root Mean Square Error of Approximation (RMSEA, values less than 0.8 are required for adequate fit (Browne & Cudeck, 1993)), the Tucker-Lewis Index (TLI, values higher than 0.9 are required for close fit (Bentler & Bonett, 1980)) and the Comparative Fit Index (CFI, values higher than 0.9 are required for close fit;).

To investigate internal consistency, Cronbach's alpha (Cronbach, 1951), alpha if item deleted, and item-total correlations were computed within each factor. Problematic items, in terms of reliability, were defined. The item-total correlations would be larger than 0.8 (redundant items) or below 0.3 (non-consistent items), and/or items that increased the reliability of omitted from the scale, indicated by alpha if item omitted.

Correlations between the SSAS total score, the Physical Functioning Subscale, and self-rated percentage school attendance and the SST were examined to investigate the concurrent, construct (discriminative and convergent) validity.

[INSERT TABLES 1 AND 2 ABOUT HERE]

RESULTS

Factor Analysis and Reliability

For the Physical Functioning Subscale (10 items), one eigenvalue above 1 emerged (7.1, with the second one being 0.8) suggesting one factor structure according to the Kaiser's criterion (also see the corresponding scree plot; Figure 1 at the Appendix). The 1-factor model

provided adequate but not close fit to the data (rel $\chi^2=2.3$; RMSEA=0.107, p-close=0.002; TLI=0.98; CFI=0.98). According to the chi-square test for nested models, increasing the number of factors to two, significantly improved the fit in our data ($\chi^2=34.714$, df= 9, p< 0.001). Indeed the 2-factor model emerged a close fit to our data (rel $\chi^2=1.7$; RMSEA=0.080, p-close=0.110); TLI=0.99; CFI=0.99). The factor structure is presented in Table 3 below.

[INSERT TABLE 3 ABOUT HERE]

Cronbach's α coefficient for the 10-item Physical Functioning Subscale was .91. As the exploratory analysis suggested two sub-scales, internal consistency was estimated within each. For the first factor (items 1, 2, 3, 4, and 10) alpha was .82, and for the second factor (items 5, 6, 7, 8, and 9) alpha was .89, suggesting satisfactory reliability for both factors.

For the SSAS 5-item scale, one eigenvalue above one was present (2.97, with the next one being 0.82 – see also the scree plot Figure 2 in the Appendix). The 1-factor model provided adequate but not close fit to the data (rel $\chi^2=5.1$; RMSEA=0.184, p-close=0.001); TLI=0.81; CFI=0.91). According to the chi-square test, by increasing the number of factors to two, the fit was not significantly improved, therefore the two-factor solution was not appropriate for this scale ($\chi^2=0.210$, df= 1, p=0.647). Cronbach's α coefficient for the 5-item SSAS was .81.

The inter-item correlations within each subscale ranged from 0.22 to 0.71 on the Physical Functioning Subscale and 0.30 to 0.63 on the SSAS. Using alpha if item deleted and item-total correlations, we did not identify any problematic items on either scale (Table 2).

Convergent and divergent validity

Convergent validity is demonstrated by the strength of the relationship between scores from different measurements. We assessed convergent validity by utilising different measures of impairment. Specifically, we expected that the Physical Functioning Scale would be moderately correlated with self-reported % school attendance and the more objective SST as they assess similar constructs. We also expected that the SSAS-total and the SSAS school-related items (school attendance and doing homework) would be moderately correlated with % school attendance. The correlations were in the expected direction (Table 4).

There was evidence of divergent validity with SST having small correlations with SSAS. There were also smaller correlations between the SSAS making friends and leisure activities items and % school attendance than there were between % school attendance and the school related items of the SSAS (school attendance, doing homework), providing further evidence of divergent validity.

[INSERT TABLE 4 ABOUT HERE]

DISCUSSION

Given the significant impact that CFS has on functioning for affected adolescents, it is important to establish whether the commonly used measures of physical, school and social functioning are valid and reliable. We found that the Physical Functioning Subscale as a measure of physical functioning appeared to be reliable and valid, although it appeared to separate into 2 factors rather than representing a single construct. The SSAS, a measure of school and social functioning, was also found to be reliable and valid. The fits for 1 factor

and 2-factor solutions were adequate but not close, suggesting that it might be tapping multiple factors.

Factor Structure

On the Physical Functioning Subscale, the items which clustered together in the factor analysis were a) vigorous activities, moderate activities, lifting and carrying, climbing many stairs, and bathing/dressing, and b) climbing few stairs, bending and kneeling, and walking any distance. However, since there were several items with substantial cross-loadings (e.g., PF4, PF10, PF5), this method of scoring is suggested tentatively. We attempted to use different rotation methods but the cross loadings were persistent. A one-dimension solution was not acceptable in our data, so it does appear that in adolescents, there are two separable dimensions of physical functioning. Based on our factor analysis, the first subscale may capture more physically demanding tasks, but also tasks that are easier to relinquish or modify. The second sub-scale appears to encompass basic activities of daily living that adolescents must engage in in their day-to-day lives. The items on the Physical Functioning Subscale could be divided into two 5-item subscales with items 1-4, and item 10 forming one subscale, called 'Physically demanding activities', and items 5-9 forming another subscale, called 'Basic physical activities'. Using the widely accepted coding method of 0 (yes, limited a lot), 5 (yes, limited a little) and 10 (no, not limited at all), each 5-item subscale would have a possible total score ranging from 0 (extremely impaired) to 50 (not impaired at all).

The SSAS is a potentially helpful assessment and outcome measure, which focuses on participation in life, encompassing a broader range of functioning than the more typically used percentage of school attendance. In adults, the Work and Social Adjustment Scale, from which the SSAS was developed, a distinct social functioning factor has been found (i.e.

a 2 factor solution) (Zahra et al., 2014), but this did not appear to be the case for adolescents with CFS in the current study. This may be because social life and school are inherently interconnected for adolescents. In adults they can be separated more easily. For example, an adult may reduce their social participation by curtailing their social activities substantially to accommodate feelings of fatigue, whilst continuing to work.

Convergent and divergent validity

We have provided some preliminary evidence of convergent validity. Physical functioning and school and social functioning were moderately associated with one another, and with time taken to complete a sit-to-stand test, which is an objective measure of physical functioning. This provides evidence of construct validity as we would theoretically expect these measures, all of which encompass functioning, to be related.

There was evidence of divergent validity as there were relatively small correlations between functioning and self-reported percentage school attendance. Being present at school (or not) is unlikely to capture the multidimensional nature of school functioning which includes academic achievement, social relationships, and extracurricular activities. Our argument for utilising the SSAS as a measure in this population was that school attendance as an index of participation and functioning in that environment is not sufficiently nuanced to capture the extent to which CFS hampers academic and social functioning, for instance, through poor concentration.

Limitations

The sample was recruited consecutively from all eligible participants who attended the CFS units during the recruitment periods, which is likely to have limited selection bias. However, we do not know whether the findings apply to those who do not attend specialist

services (for example, those who are managed in primary care settings). Furthermore, we assumed homogeneity across the 2 recruitment sites, but were not able to control for collection site in our analyses, which may have led to biases. Given the small number of participants recruited from the second site, this is unlikely. The Physical Functioning Subscale is a subscale of a larger (36 item) scale, and only this subscale was used in the current study. Although the brevity of the school and social functioning measure is appealing, it could be argued that it still does not cover all the facets of school and social functioning, as it may, for example, neglect concentration and attention within the classroom environment. In this study, we have relied primarily on self-report scales, although a strength is the inclusion of the SST as an objective measure of functioning. The current study explored some of the psychometric properties of these measures, but further research is required to assess test-retest reliability, group differences, and treatment sensitivity. In the current study, a second sample that could potentially be used to confirm the factor structure via confirmatory factor analysis, was not available.

Conclusions

CFS is a debilitating illness, which affects functioning across multiple domains, including school and social functioning, and physical functioning. In adolescence, this interferes with school attendance and performance. Having brief, reliable and valid measures of functioning in these domains is important to inform assessment and management of CFS-related disability in school students.

Measures are often used with adolescents which have been developed for adults. However, due to the developmental and contextual differences of young people, these may need to be adapted or interpreted differently in this specific population. We found some evidence of reliability and validity of the 2 measures we tested. We also found that the

physical functioning scale may be better conceptualised as 2 factors, basic physical activities, and physically demanding activities. The SSAS may encompass several aspects of functioning, although the fit as a single construct was acceptable. As physical, school and social functioning are important aspects of health to assess in adolescents with CFS, we have shown that these measures provide a way to do this, although further psychometric investigation is warranted. As these measures were developed for adults, a preferable approach with better face validity may be developing measures specifically for adolescents.

Human Subjects Approval Statement

Approval was granted by NHS research ethics committee (LREC, ref 08/H0807/107), and by the Research and Development departments at the South London and Maudsley (SLaM) NHS Trust, and Great Ormond Street Hospital. Approval for the collection of routine outcome measures was also given by the clinical audit committee of Psychological Medicine Clinical academic group of SLaM.

Acknowledgements

[not included here for blinding purposes]

Table 1. Participant demographics and scores on Physical Functioning Subscale and SSAS

| | | N (%) | | |
|---------------------------------------|---------------------|---------------|--------|--|
| Gender | Male | 35 (28.9) | | |
| | Female | 86 (71.1) | | |
| Ethnic Origin | White British | 86 (71.1) | | |
| | Black British | 2 (1.7) | | |
| | Asian/British Asian | 3 (2.5) | | |
| | British other | 11 (9.1) | | |
| | Other European | 3 (2.5) | | |
| | Other White | 11 (9.1) | | |
| | Mixed race | 4 (3.3) | | |
| | Not stated | 4 (3.3) | | |
| | | | | |
| | Range (Min-Max) | Mean (S.D.) | Median | |
| Age in years – mean (S.D.) | 11-18 | 15.0 (1.71) | | |
| Physical Functioning Subscale | | | | |
| Item 1: Vigorous activities | 0-10 | 0.97 (2.20) | 0 | |
| Item 2: Moderate activities | 0-10 | 4.29 (3.67) | 5 | |
| Item 3: Lifting/carrying | 0-10 | 5.92 (3.30) | 5 | |
| Item 4: Climbing Many Stairs | 0-10 | 3.07 (3.55) | 0 | |
| Item 5: Climbing Few Stairs | 0-10 | 6.27 (3.44) | 5 | |
| Item 6: Bending/kneeling | 0-10 | 6.55 (3.66) | 5 | |
| Item 7: Walking < 1 mile | 0-10 | 2.81 (3.41) | 0 | |
| Item 8: Walking several hundred yards | 0-10 | 5.31 (3.75) | 5 | |
| Item 9: Walking 100 yards | 0-10 | 7.28 (3.21) | 10 | |
| Item 10: Bathing/dressing | 0-10 | 7.50 (3.21) | 10 | |
| Total score | 0-100 | 50.05 (25.33) | 50 | |
| SSAS | | | | |
| Item 1: School attendance | 1-8 | 6.45 (1.65) | 7 | |
| Item 2: Doing homework | 0-8 | 5.67 (2.03) | 6 | |
| Item 3: Social leisure activities | 0-8 | 5.87 (1.81) | 6 | |
| Item 4: Private leisure activities | 0-8 | 3.17 (2.27) | 3 | |
| Item 5: Making friends | 0-8 | 3.45 (2.78) | 3 | |
| Total score | 4-40 | 24.30 (8.05) | 25 | |

Table 2. Items included in SSAS and Physical Functioning Subscale measures and reliability indices at item level

| Physical Functioning Subscale Statement posed to participant with response options ‘yes, limited a lot’, ‘yes, limited a little’, ‘no, not limited at all’ | | Reliability Indices | |
|---|--|----------------------------|------------|
| | | AID | ITC |
| PF1 | <u>Vigorous activities</u> , such as running, lifting heavy objects, participating in strenuous sports | .92 | .45 |
| PF2 | <u>Moderate activities</u> such as moving a table, pushing a vacuum cleaner, bowling or playing golf | .90 | .72 |
| PF3 | Lifting or carrying groceries | .90 | .73 |
| PF4 | Climbing <u>several</u> flights of stairs | .90 | .70 |
| PF5 | Climbing <u>one</u> flight of stairs | .90 | .82 |
| PF6 | Bending, kneeling or stooping | .91 | .67 |
| PF7 | Walking <u>more than a mile</u> | .91 | .63 |
| PF8 | Walking <u>several hundred yards</u> | .90 | .79 |
| PF9 | Walking <u>one hundred yards</u> | .90 | .73 |
| PF10 | Bathing or dressing yourself | .91 | .58 |

| Item Label | SSAS Statement posed to participant with response options: | | | | | | | | | | Reliability Indices | |
|-------------------|--|----------|---|------------|---|----------|---|---------------|---|--|----------------------------|------------|
| | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | | AID | ITC |
| | Not at all | Slightly | | Definitely | | Markedly | | Very severely | | | | |
| SSAS1 | Because of my illness my ability to attend school/college/work is impaired. | | | | | | | | | | .78 | .51 |
| SSAS2 | Because of my illness my ability to do homework is impaired. | | | | | | | | | | .77 | .45 |
| SSAS3 | Because of my illness my social leisure activities are impaired (with other people e.g. parties, outings, seeing friends). | | | | | | | | | | .75 | .52 |
| SSAS4 | Because of my illness my private leisure activities are impaired (done alone, e.g., reading, watching t.v., listening to music). | | | | | | | | | | .76 | .44 |
| SSAS5 | Because of my illness my ability to make friends is impaired. | | | | | | | | | | .81 | .35 |

AID = α if item deleted; ITC = Item-total correlation, SSAS = School and social adjustment scale

Table 3. Factor structure for Physical Functioning Subscale

| | | | |
|-------------|--|-------------|--------------|
| PF2 | <u>Moderate activities</u> such as moving a table, pushing a vacuum cleaner, bowling or playing golf | 1.05 | -0.10 |
| PF3 | Lifting or carrying groceries | 0.80 | 0.12 |
| PF1 | <u>Vigorous activities</u> , such as running, lifting heavy objects, participating in strenuous sports | 0.70 | 0.06 |
| PF4 | Climbing <u>several</u> flights of stairs | 0.50 | 0.44 |
| PF10 | Bathing or dressing yourself | 0.48 | 0.31 |
| PF9 | Walking <u>one hundred yards</u> | -0.05 | 1.00 |
| PF8 | Walking <u>several hundred yards</u> | 0.00 | 0.96 |
| PF6 | Bending, kneeling or stooping | 0.13 | 0.72 |
| PF5 | Climbing <u>one</u> flight of stairs | 0.42 | 0.61 |
| PF7 | Walking <u>more than a mile</u> | 0.24 | 0.58 |

Table 4. Pearson's correlation coefficient – $r(p)$ between Physical Functioning Subscale, SSAS scores and selected measures

| SF36 Physical Functioning Subscale | | | |
|---|---|--------------------------------------|--------------------------------------|
| Variable | Physical Function subscale total score | Physical Functioning Factor 1 | Physical Functioning Factor 2 |
| SSAS total | -0.58 (<.001) | -0.61 (<.001) | -0.48 (<.001) |
| % School attendance | 0.32 (.002) | 0.27 (.008) | 0.33 (.001) |
| SST | -0.42 (.001) | -0.31 (.021) | -0.43 (.001) |
| SSAS | | | |
| Variable | SSAS-total score | | |
| Physical Functioning Subscale | -0.5 (<.001) | | |
| % School attendance | -0.37 (<.001) | | |
| SST | 0.53 (<.01) | | |

SSAS = School and social adjustment scale; SST = Sit-to-stand test (time taken)

Higher scores on Physical Functioning Scale indicate better functioning; higher scores on SSAS indicate greater impairment in functioning.

Figure S1. Scree plot for Physical Functioning Subscale

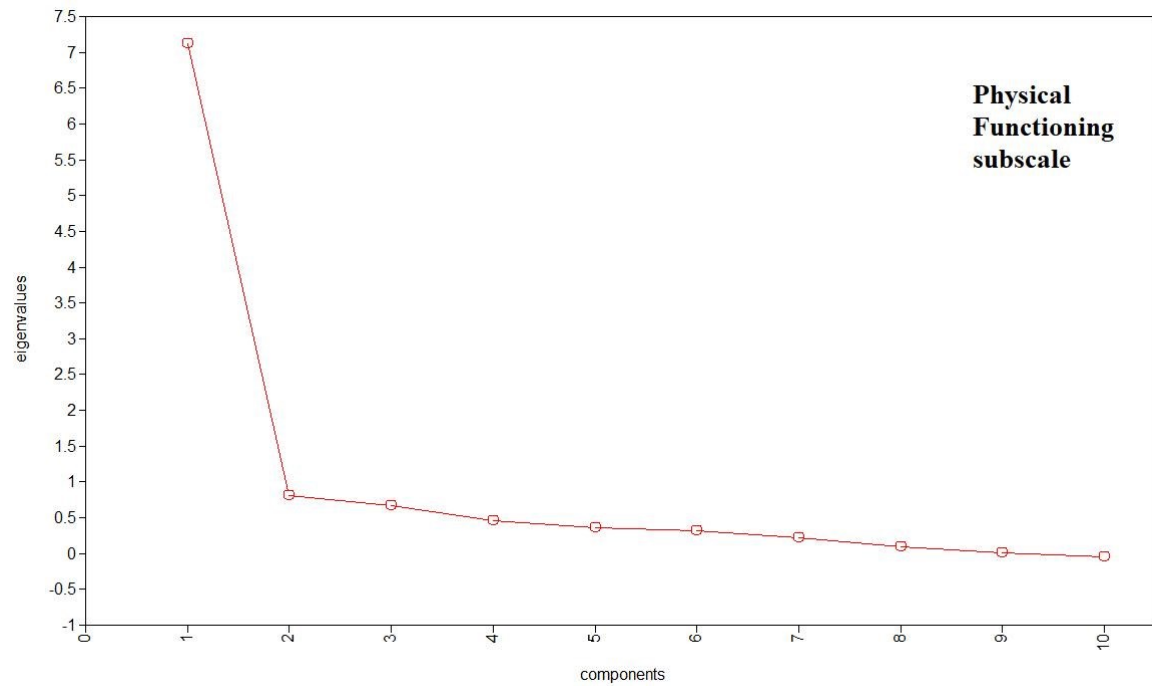
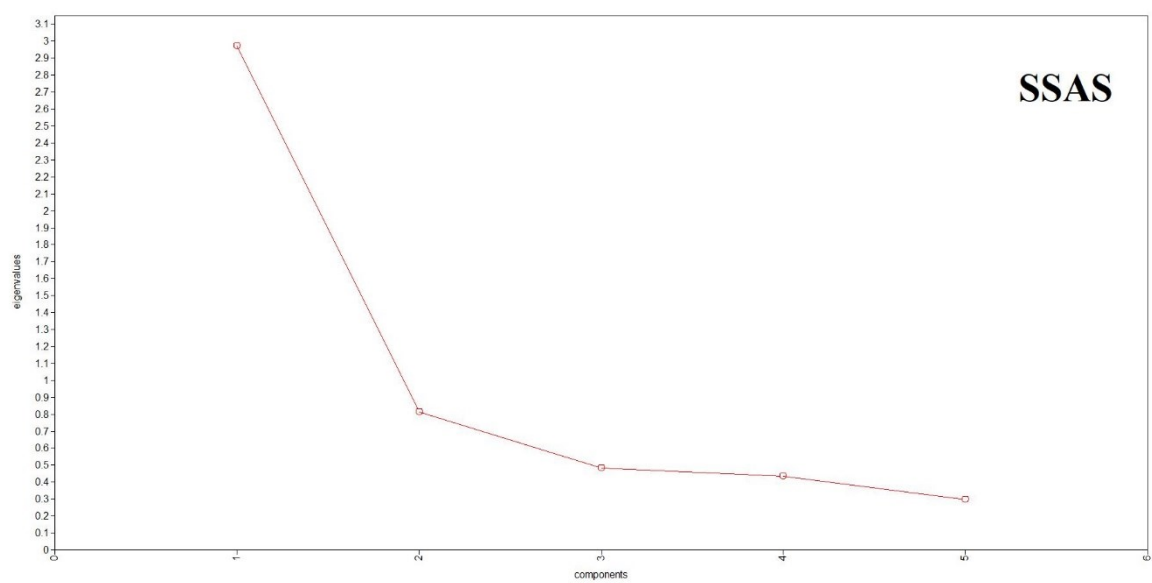


Figure S2. Scree plot for School and Social Functioning Scale



REFERENCES

- Bentler, P. M., & Bonett, D. G. (1980). Significance tests and goodness of fit in the analysis of covariance structures. *Psychological bulletin*, 88(3), 588.
- Bohannon, R. W. (2011). Test-retest reliability of the five-repetition sit-to-stand test: a systematic review of the literature involving adults. *J Strength Cond Res*, 25(11), 3205-3207. doi:10.1519/JSC.0b013e318234e59f
- Bould, H., Collin, S. M., Lewis, G., Rimes, K. A., & Crawley, E. (2013). Depression in paediatric chronic fatigue syndrome. *Arch Dis Child*, 98(6), 425-428. doi:10.1136/archdischild-2012-303396
- Brigden, A., Beasant, L., Hollingworth, W., Metcalfe, C., Gaunt, D., Mills, N., . . . Crawley, E. (2016). Managed Activity Graded Exercise in Teenagers and pre-Adolescents (MAGENTA) feasibility randomised controlled trial: study protocol. *BMJ Open*, 6(7), e011255. doi:10.1136/bmjopen-2016-011255
- Brigden, A., Loades, M., Abbott, A., Bond-Kendall, J., & Crawley, E. (2017). Practical management of chronic fatigue syndrome or myalgic encephalomyelitis in childhood. *Arch Dis Child*, archdischild-2016-310622.
- Browne, M. W., & Cudeck, R. (1993). Alternative ways of assessing model fit. *Sage focus editions*, 154, 136-136.
- Burgess, M., Andiappan, M., & Chalder, T. (2012). Cognitive behaviour therapy for chronic fatigue syndrome in adults: Face to face versus telephone treatment-A randomized controlled trial. *Behav Cogn Psychother*, 40(2), 175-191.
- Cattell, R. (1978). *The scientific use of factor analysis in behavioral and life sciences*: Springer Science & Business Media.
- Cella, M., Sharpe, M., & Chalder, T. (2011). Measuring disability in patients with chronic fatigue syndrome: reliability and validity of the Work and Social Adjustment Scale. *J Psychosom Res*, 71(3), 124-128.
- Chalder, T., Berelowitz, G., Pawlikowska, T., Watts, L., Wessely, S., Wright, D., & Wallace, E. (1993). Development of a fatigue scale. *J Psychosom Res*, 37(2), 147-153.
- Chalder, T., Deary, V., Husain, K., & Walwyn, R. (2010). Family-focused cognitive behaviour therapy versus psycho-education for chronic fatigue syndrome in 11- to 18-year-olds: a randomized controlled treatment trial. *Psychol Med*, 40(08), 1269-1279. doi:10.1017/S003329170999153X
- Crawley, E., Gaunt, D. M., Garfield, K., Hollingworth, W., Sterne, J. A. C., Beasant, L., . . . Montgomery, A. A. (2017). Clinical and cost-effectiveness of the Lightning Process in addition to specialist medical care for paediatric chronic fatigue syndrome: randomised controlled trial. *Arch Dis Child*. doi:10.1136/archdischild-2017-313375
- Crawley, E., & Sterne, J. A. (2009). Association between school absence and physical function in paediatric chronic fatigue syndrome/myalgic encephalopathy. *Arch Dis Child*, 94(10), 752-756. doi:10.1136/adc.2008.143537
- Cronbach, L. J. (1951). Coefficient alpha and the internal structure of tests. *psychometrika*, 16(3), 297-334.
- Csuka, M., & McCarty, D. J. (1985). Simple method for measurement of lower extremity muscle strength. *American Journal of Medicine*, 78(1), 77-81.
- de Winter*, J. d., Dodou*, D., & Wieringa, P. A. (2009). Exploratory factor analysis with small sample sizes. *Multivariate behavioral research*, 44(2), 147-181.
- Deale, A., Chalder, T., Marks, I., & Wessely, S. (1997). Cognitive behavior therapy for chronic fatigue syndrome: a randomized controlled trial. *American Journal of Psychiatry*, 154(3), 408-414.
- Garralda, M. E., & Rangel, L. (2004). Impairment and coping in children and adolescents with chronic fatigue syndrome: a comparative study with other paediatric disorders. *J Child Psychol Psychiatry*, 45(3), 543-552.

- Gordon, B. A., Knapman, L. M., & Lubitz, L. (2010). Graduated exercise training and progressive resistance training in adolescents with chronic fatigue syndrome: a randomized controlled pilot study. *Clin Rehabil*, 24(12), 1072-1079. doi:10.1177/0269215510371429
- Hoelter, J. W. (1983). The analysis of covariance structures: Goodness-of-fit indices. *Sociological Methods & Research*, 11(3), 325-344.
- Lloyd, S., Chalder, T., & Rimes, K. A. (2012). Family-focused cognitive behaviour therapy versus psycho-education for adolescents with chronic fatigue syndrome: long-term follow-up of an RCT. *Behav Res Ther*, 50(11), 719-725. doi:10.1016/j.brat.2012.08.005
- Lloyd, S., Chalder, T., Sallis, H. M., & Rimes, K. A. (2012). Telephone-based guided self-help for adolescents with chronic fatigue syndrome: A non-randomised cohort study. *Behav Res Ther*, 50(5), 304-312. doi:10.1016/j.brat.2012.02.014
- May, M., Emond, A., & Crawley, E. (2010). Phenotypes of chronic fatigue syndrome in children and young people. *Arch Dis Child*, 95(4), 245-249.
doi:<http://dx.doi.org/10.1136/adc.2009.158162>
- McHorney, C. A., Ware Jr, J. E., & Raczek, A. E. (1993). The MOS 36-Item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. *Medical care*, 247-263.
- Mundt, J. C., Marks, I. M., Shear, M. K., & Greist, J. M. (2002). The Work and Social Adjustment Scale: a simple measure of impairment in functioning. *The British Journal of Psychiatry*, 180(5), 461-464.
- Muthén, B., du Toit, S., & Spisic, D. (1997). Robust interference using weighted least squares and quadratic estimating equations in the latent variable modeling with categorical and continuous outcomes. *Unpublished manuscript, University of California, Los Angeles, USA*.
- Muthén, L. K., & Muthén, B. O. (1998). Mplus user's guide (Version 7). Los Angeles, CA: Author.
- NICE. (2007). *Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): Diagnosis and management of CFS/ME in adults and children*.
- Parslow, R. M., Harris, S., Broughton, J., Alattas, A., Crawley, E., Haywood, K., & Shaw, A. (2017). Children's experiences of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME): a systematic review and meta-ethnography of qualitative studies. *BMJ Open*, 7(1), e012633. doi:10.1136/bmjopen-2016-012633
- Quarmby, L., Rimes, K. A., Deale, A., Wessely, S., & Chalder, T. (2007). Cognitive-behaviour therapy for chronic fatigue syndrome: comparison of outcomes within and outside the confines of a randomised controlled trial. *Behav Res Ther*, 45(6), 1085-1094. doi:10.1016/j.brat.2006.08.019
- RCPCH. (2004). *Evidence Based Guideline for the Management of CFS/ME (Chronic Fatigue Syndrome/ Myalgic Encephalopathy) in Children and Young People*. In Royal College of Paediatrics and Child Health. Retrieved from <http://www.rcpch.ac.uk/rcpch-guidelines-and-standards-clinical-practice#cfs-me>
- Sankey, A., Hill, C. M., Brown, J., Quinn, L., & Fletcher, A. (2006). A follow-up study of chronic fatigue syndrome in children and adolescents: symptom persistence and school absenteeism. *Clin Child Psychol Psychiatry*, 11(1), 126-138.
- Sharpe, M. C., Archard, L. C., Banatvala, J. E., Borysiewicz, L. K., Clare, A. W., David, A., . . . Lane, R. J. (1991). A report--chronic fatigue syndrome: guidelines for research. *Journal of the Royal Society of Medicine*, 84(2), 118-121.
- Stulemeijer, M., de Jong, L. W., Fiselier, T. J., Hoogveld, S. W., & Bleijenberg, G. (2005). Cognitive behaviour therapy for adolescents with chronic fatigue syndrome: randomised controlled trial. *BMJ*, 330(7481), 14. doi:10.1136/bmj.38301.587106.63
- Thandi, G., Fear, N. T., & Chalder, T. (2017). A comparison of the Work and Social Adjustment Scale (WSAS) across different patient populations using Rasch analysis and exploratory factor analysis. *J Psychosom Res*, 92, 45-48.

- Tollit, M., Politis, J., & Knight, S. (2018). Measuring School Functioning in Students With Chronic Fatigue Syndrome: A Systematic Review. *Journal of School Health, 88*(1), 74-89.
- Tomey, K. M., & Sowers, M. R. (2009). Assessment of physical functioning: a conceptual model encompassing environmental factors and individual compensation strategies. *Physical therapy, 89*(7), 705.
- Ware, J. E., & Sherbourne, C. D. (1992). The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. *Medical care, 473-483*.
- White, P. D., Goldsmith, K. A., Johnson, A. L., Potts, L., Walwyn, R., DeCesare, J. C., . . . Cox, D. (2011). Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. *The Lancet, 377*(9768), 823-836.
- Zahra, D., Qureshi, A., Henley, W., Taylor, R., Quinn, C., Pooler, J., . . . Byng, R. (2014). The work and social adjustment scale: reliability, sensitivity and value. *International journal of psychiatry in clinical practice, 18*(2), 131-138.